

# Report on Strategic Planning Workgroup Meeting

Judith Cooper, Ph.D.

NIDCD

IACC Meeting - July 15<sup>th</sup>, 2008

# SPWG Meeting Forum

- SPWG held its second meeting on July 8<sup>th</sup>, 2008 to provide first-read and comment on the Draft ASD Strategic Plan
- Held as a webinar open to the public
- 76 people, including the SPWG, IACC members and the public listened into the meeting
- The comments summarized here are from individuals, not consensus

# SPWG Participants

- **Thomas Insel, M.D. (chair)** NIMH
- **David Amaral, Ph.D.** University of California, Davis
- **Peter Bell MBA** Autism Speaks
- **Mark F. Blaxill MBA** Coalition for Safe Minds
- **Judith Cooper, Ph.D.** NIDCD
- **Geraldine Dawson, Ph.D.** Autism Speaks
- **Steve Eiken, M.A.** Thomson Healthcare
- **Daniel Geschwind, M.D., Ph.D.** UCLA
- **Martha Herbert, M.D., Ph.D.** Harvard Medical School
- **Alice Kau, Ph.D.** NICHD
- **Catherine Lord, Ph.D.** University of Michigan
- **David Mandell, Sc.D.** University of Pennsylvania
- **Prisca Chen Marvin, J.D.**
- **Sam Odom, Ph.D.** University of North Carolina
- **Isaac Pessah, Ph.D.** University of California, Davis
- **Denise D. Resnik** SARRC
- **Edwin Trevathan, M.D., MPH** CDC
- **Lucille Zeph, Ed. D.** University of Maine

# Status of Draft Plan

- Draft SP is not a final plan because it does not include the budgetary requirements
- The Draft SP will need to go out for public comment
- Services ASD research is included in this plan but services provision is not

# SPWG Meeting: Overview of Themes

- Enhance and clarify language to capture more effectively the values and goals put forth by the IACC
- Strengthen the integration of cross-cutting themes within the objectives
- More effectively convey the sense of urgency as expressed by the ASD community

# Individual Comments to the Introduction and Cross-Cutting Themes

- Strengthen:
  - Sense of urgency
  - Importance of prevention
- Describe need for cutting edge science
- Early detection:
  - Prenatal
  - Postnatal
  - Early Childhood
- Expansion of Heterogeneity to Include:
  - Disease
  - Risk Factors
  - Treatments and Interventions
  - Balanced with common features
- Partnership between the ASD and Research communities

# Question 1

**WHEN SHOULD I BE CONCERNED?**

# Individual Comments on Question 1

- Collaboration with existing culturally competent resources to facilitate recruitment in underserved communities
- Strengthen the biomarker discussion to include postnatal genetic and gene x environment research
- Initiation of immediate biomarker research
- Early detection informed by linking developmental trajectory and biological processes
- Detection of regression in ASD



# Question 2

HOW CAN I UNDERSTAND WHAT IS  
HAPPENING?

# Individual Comments on Question 2

- The importance of immune and other medical problems in understanding ASD
- Expand access to biospecimens to include other tissues beyond brain, such as skin fibroblasts
- Sharpen the focus of the 2nd short-term objective to include immune and metabolic interactions with the CNS
- Expand the Long-Term objective to include youth and adults; extend timeframe to 2030; examine how symptoms change over time
- Balance the Aspirational Goal to include interventions applicable to a wide range of individuals

# Question 3

WHAT CAUSED THIS TO HAPPEN AND  
CAN THIS BE PREVENTED?

# Individual Comments on Question 3

- Expand environmental factors section in “What do we know”
  - Example: toxicology resources and informatics infrastructure as avenues for collaboration to study ASD
- Specific objective on vaccine research? Does the current broader wording on environmental factors capture the issue?
- Include an objective on developing cellular high throughput systems
- Testing the impact of environmental factors, using cell lines from individuals with ASD
- Development of international resources and perspective
- Discontinue use of ‘preemption’; stay with prevention

# Question 4

WHICH INTERVENTIONS WILL HELP?

# Individual Comments on Question 4

- Expand the Aspirational Goal to also focus on strengthening adaptive and positive outcomes
- Balance discussion of possible treatments to give more support for study of treatments in current wide use by parents and families
- Emphasize need for methods and designs that permit identifying what works best and for which individuals
  - This will help identify sub-groups as well as possible mechanisms
  - Will encourage “bedside to bench” translational research
- Strengthen emphasis on school-age, adolescence, and adulthood

# Question 5

WHERE CAN I TURN FOR SERVICES?

# Individual Comments on Question 5

- Within “What we know”; replace section on prevalence with services and communities of care and support
- Revise the Aspirational Goal to read as follows:
  - Communities will implement high quality, research-based, and cost-effective services for supporting quality of life across the lifespan for individuals with ASD
- Partnership between the ASD and Research communities
- Add a short-term objective to assess how variations and access to services post-diagnosis affect families
- Expand the 2nd long-term objective to include process analysis about what allows the model to be effective
- Add an objective to build infrastructure/resource that systematically records families experiences to interventions and treatments



# Question 6

WHAT DOES THE FUTURE HOLD?

# Individual Comments on Question 6

- Add a long-term objective to study the long-term effects of early intervention programs on adulthood, including study of how costs of early intervention affect adult needs and costs
- Expand to include mention of potential opportunities to partner across agencies and private sector to launch more research on adult population

# Comments about Implementation

- Budgetary requirements
  - Determine who will provide funding, for which projects, and through what mechanisms
- Establish process for prioritizing treatment and intervention research
- Determine how to identify what works best and for which individuals
- Members of the WG are willing to participate